

**IN THE UNITED STATES DISTRICT COURT
FOR THE MIDDLE DISTRICT OF TENNESSEE
NASHVILLE DIVISION**

M.A.C., by next friend,
M.E.C.,
SCARLET BURK, by next friend,
Felicia Burk;
BINTA BARROW, by next friend
Sadiatou Ashford;
JAY BRYANT, by next friend,
Drama Bryant;
AMANDA CASEY, by next friend,
Ronda Coggins;

Plaintiffs

vs.

STEPHEN SMITH, in his official capacities
as Deputy Commissioner of the Tennessee
Department of Finance and Administration
and Director of TennCare; and the
TENNESSEE DEPARTMENT OF
FINANCE AND ADMINISTRATION,

Defendants.

Civil Action No. _____

**COMPLAINT FOR DECLARATORY
AND INJUNCTIVE RELIEF**

INTRODUCTION

1. Plaintiffs are young people with severe intellectual disabilities and medical conditions who are enrolled in the State of Tennessee's Medicaid program, known as TennCare. They are also enrolled in a special TennCare program, administered by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD), known as the "DIDD Waiver," whose purpose is to enable them to live at home with their families and prevent their involuntary

institutionalization. The State acknowledges that the Plaintiffs require extensive care, including personal attendant (PA) services to enable them to live safely at home.

2. The State nonetheless fails to provide the in-home care required to meet the Plaintiffs' acknowledged needs. As a result, the Plaintiffs repeatedly experience gaps in their care, causing preventable suffering, harm to their health and heightened risk of involuntary institutionalization, all in violation of the federal Medicaid Act and its implementing regulations.

3. The State's chronic failure to meet the Plaintiffs' care needs is due to the State's longstanding insistence on paying lower rates for home care services, including PA services, for people in the DIDD Waiver than TennCare pays for identical services provided to all other TennCare enrollees. The policy has deterred agencies from contracting with TennCare, resulting in a provider network that is grossly inadequate to meet the needs of many DIDD Waiver participants like the Plaintiffs. The State recently improved DIDD'S rates for PA services, but left rates for other DIDD providers well below the rates that the State pays for the care of all other TennCare enrollees. As a result, agencies remain unwilling to contract with DIDD, and the DIDD Waiver remains incapable of meeting the Plaintiffs' needs for PA services. The State's policy discriminates against the Plaintiffs on the basis of their intellectual disabilities in violation of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. The State also violates the ADA by offering the Plaintiffs the care they need in an institutional setting, while withholding care in a home and community-based setting, in defiance of the ADA's requirement that services be provided in the most integrated setting appropriate to the individual's needs.

4. Plaintiffs Scarlet Burk and M.A.C. are under 21 and are therefore also entitled under the Medicaid Act to receive Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services. Under this entitlement, the State must provide them all covered health care

services that are medically necessary to correct or ameliorate defects and physical and mental illnesses. 42 U.S.C. § 1396d(a)(4); 42 U.S.C. § 1396d(r). Covered services include home health care services, personal care services and “other medical or remedial services recommended by a physician ... for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.” 42 U.S.C. § 1396d(a)(7), (24); 42 U.S.C. § 1396d(r). The State’s failure to provide the health care they need deprives Plaintiffs Burk and M.A.C. of their right to medically necessary EPSDT services.

5. The State has compounded the harm inflicted on the Plaintiffs by denying them the opportunity to appeal and receive a fair hearing to remedy the wrongful denial of necessary health services.

6. The Plaintiffs bring this suit against the Director of TennCare in his official capacity, as well as against the Tennessee Department of Finance Administration, the public entity responsible for administration of the TennCare program. The Plaintiffs seek a declaratory judgment that the TennCare practices of which they complain are invalid under the Medicaid Act, the ADA, Section 504 of the Rehabilitation Act, and the Due Process Clause of the Fourteenth Amendment of the United States Constitution. The Plaintiffs request preliminary and permanent injunctive relief prohibiting the defendants from continuing to withhold the care all parties agree they need in their home.

JURISDICTION AND VENUE

7. Jurisdiction is conferred on this Court by 28 U.S.C. § 1331, which provides for original jurisdiction over all civil suits involving questions of federal law; 28 U.S.C. § 1343(3), which confers original jurisdiction over actions brought under 42 U.S.C. § 1983 and 29 U.S.C. §

794; and by 42 U.S.C. § 12133, which provides original jurisdiction over actions arising under Title II of the ADA.

8. Plaintiff seeks declaratory, injunctive, and other appropriate relief, pursuant to 28 U.S.C. § 2201 and 42 U.S.C. § 12132.

9. Venue is proper pursuant to 28 U.S.C. § 1391(b), because a substantial part of the events or omissions giving rise to the claims occurred in this District.

PARTIES

Plaintiffs

10. Plaintiff M.A.C. is a 17-year-old resident of Clarkesville, Montgomery County, Tennessee. As authorized by Fed. R. Civ. P. 17(c)(2), she brings this action through her mother, M.E.C., acting as her next friend.

11. Plaintiff Scarlet Burk is a 19-year-old resident of Fayetteville, Lincoln County, Tennessee. As authorized by Fed. R. Civ. P. 17(c)(2), she brings this action through her mother, Felicia Burk, acting as her next friend.

12. Plaintiff Binta Barrow is a 25-year-old resident of Knoxville, Knox County, Tennessee. As authorized by Fed. R. Civ. P. 17(c)(2), she brings this action by her mother, Sadiatou Jallow, acting as her next friend.

13. Plaintiff Jay Bryant is a 32-year-old resident of Mohawk, Greene County, Tennessee. As authorized by Fed. R. Civ. P. 17(c)(2), he brings this action through his sister, Drama Bryant, acting as his next friend.

14. Plaintiff Amanda Casey is a 41-year-old resident of Telford, Washington County, Tennessee. As authorized by Fed. R. Civ. P. 17(c)(2), she brings this action through her mother, Ronda Coggins, acting as her next friend.

Defendants

15. Defendant Stephen Smith is sued in his official capacities as Deputy Commissioner of the Tennessee Department of Finance and Administration (“DFA”) and Director of that Department’s Division of TennCare (hereafter referred to as “TennCare”). Defendant Smith oversees all aspects of the TennCare program and acts under color of state law.

16. Defendant Tennessee Department of Finance and Administration is an executive agency of the State of Tennessee. DFA is Tennessee’s “single state agency,” within the meaning of 42 U.S.C. § 1396a(a)(5) and 42 C.F.R. § 431.10, that is responsible for administering the TennCare program. The Division of TennCare is the division within DFA that directly manages TennCare.

FACTUAL ALLEGATIONS

Overview of the TennCare Program

17. Title XIX of the Social Security Act, known as the Medicaid Act, provides medical assistance to certain eligible individuals. 42 U.S.C. § 1396 et seq. The purpose of Medicaid is to furnish, as far as practicable, “medical assistance on behalf of . . . aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services” and “to help such families and individuals to attain or retain capability for independence or self-care . . .” 42 U.S.C. § 1396-1.

18. The federal government funds approximately two-thirds of the cost of all medical services covered by Tennessee’s Medicaid program. For the duration of the national health

emergency caused by the coronavirus pandemic, the federal government share exceeds 75% of the costs of medical services. 85 FR 76586 (November 30, 2020).

19. Medicaid is administered at the federal level by the Centers for Medicare & Medicaid Services (“CMS”) of the Department of Health and Human Services (“HHS”). Pursuant to the ADA, CMS has reminded states of their legal obligation to avoid unnecessary institutionalization of persons with disabilities, telling state Medicaid directors that “no one should have to live in an institution or a nursing home if they can live in the community with the right support.” (Exhibit 1, State Medicaid Director letter, January 14, 2000.)¹

20. Each state decides whether to participate in the Medicaid program, and all fifty states do. Tennessee has participated in Medicaid continuously since 1968. Once a state elects to participate in Medicaid, it must administer the program subject to federal requirements imposed by the Medicaid Act, the ADA and Section 504 of the Rehabilitation Act and the regulations that implement those laws.

21. Each participating state must designate a “single state agency” to administer the program consistent with federal law. 42 U.S.C. § 1396a(a)(5). The designated agency remains “legally responsible for problems with a state’s Medicaid program notwithstanding delegations of authority to other state agencies or private parties.” *Wilson v. Gordon*, 822 F.3d 934, 953 (6th Cir. 2016). Pursuant to Tenn. Code Ann. § 71-5-124 and an executive order dated October 19, 1999, the Department of Finance and Administration (DFA) is designated as the single state agency in Tennessee that administers TennCare.

¹ The letter is available at <https://aspe.hhs.gov/system/files/aspe-files/65801/primap2.pdf>. Exhibit 1 to this complaint excerpts pertinent parts of the letter.

22. In 1993, Tennessee obtained from the Secretary of HHS a Medicaid demonstration waiver under Section 1115 of the Social Security Act, 42 U.S.C. § 1315. The waiver permitted the State to replace its conventional Medicaid program with a demonstration program called TennCare. The five-year waiver was implemented in January 1994 and has been periodically revised and renewed since then pursuant to 42 U.S.C. § 1315(e). Under the terms of the waiver, TennCare medical services are managed by commercial intermediaries that subcontract with health care providers. The intermediaries are known as managed care organizations, or “MCOs.”

23. States participating in the Medicaid program must cover certain mandatory services for most Medicaid beneficiaries. See 42 U.S.C. § 1396a(a)(10)(A)(i) (incorporating 42 U.S.C. § 1396d(a)(1)-(5), (17), (21)). The Medicaid Act also allows states to cover certain other services at state option. *Id.*

24. Each service covered in a state’s Medicaid State Plan must be sufficient in amount, duration, and scope to reasonably achieve its purpose. 42 U.S.C. § 1396a(a)(10)(B); 42 C.F.R. § 440.225.

25. A state may not arbitrarily deny or reduce the amount or scope of a covered service based solely on the diagnosis or type of illness or condition of the Medicaid recipient. 42 C.F.R. § 440.230(c).

26. Home health services are an optional service under the Medicaid Act. 42 U.S.C. § 1396d(a)(7); 42 U.S.C. § 1396a(a)(10)(A). Home health services includes assisting patients with activities of daily living such as eating, toileting, transferring, etc. 42 C.F.R. § 440.70(c)(1). Home health services can be provided by nurses, certified nurse attendants (CNAs) and home health aides. *See* 42 C.F.R. § 440.70(b). Under the regulation, the state has the option to provide home health services in the beneficiary’s home. 42 C.F.R. § 440.70(a). TennCare covers home health

services in a beneficiary's home, subject to certain conditions and limitations. Tenn. Comp. R. & Regs. R. 1200-13-13-.01(57), -.04(1)(b)(9), -.04(6)(a).

27. Personal care attendant (also known as “personal attendant” or PA) services are an optional service. 42 U.S.C. § 1396d(a)(24). Like home health aide services, personal care services include assisting patients with activities of daily living such as eating, toileting, transferring, etc. Personal care services are defined as authorized services provided to an individual who is not an inpatient in an institution. 42 C.F.R. § 440.167. TennCare provides PA services as medically necessary for children under age 21, choosing to cover the service as a home health aide service delivered as part of the home health benefit. Tenn. Comp. R. & Regs. R. 1200-13-13-.01(92).

28. The Medicaid Act also requires state Medicaid agencies to provide “early and periodic screening, diagnostic, and treatment” (EPSDT) services to eligible children under the age of 21. 42 U.S.C. § 1396d(a)(4); 42 U.S.C. § 1396d(r). The State must provide children all covered health care services that are medically necessary to correct or ameliorate defects and physical and mental illnesses. *John B. v. Menke*, 176 F. Supp. 2d 786, 790 (M.D. Tenn. 2001). Covered services include home health, personal care and “other medical or remedial services recommended by a physician ... for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.” 42 U.S.C. § 1396d(a)(7)-(8); 42 U.S.C. § 1396d(r). TennCare covers home health aide services and PA services delivered as part of the home health benefit as medically necessary for children under 21 to comply with EPSDT requirements. Tenn. Comp. R. & Regs. R. 1200-13-13-.01(57)(a)(2), (101)(d).

29. TennCare provides services in institutions formerly known as intermediate care facilities for the mentally retarded, and now more commonly referred to as intermediate care facilities for individuals with intellectual disabilities (“ICF/IID”), as authorized by 42 U.S.C. §

1396d(a)(15); Tenn. Comp. R. & Regs. R. 1200-13-01-.30. The state must ensure that each resident admitted to such a facility receives all medical and nursing services necessary to meet their individual needs, as prescribed in a plan of care that is professionally reviewed on a regular basis. 42 U.S.C. § 1396a(a)(31). Specifically, residents of such facilities are entitled to receive any assistance with activities of daily living that they require to maintain their health and safety. Such care is typically provided by certified nurse assistants (CNAs), whose functions in an institutional setting are equivalent to those of home health aides or personal care attendants in a home setting. These different categories of staff performing the same functions are referred to collectively as Direct Service Providers or Direct Service Professionals (DSPs).

30. TennCare provides home and community-based services (“HCBS”) to individuals who are eligible by virtue of their medical needs and intellectual disabilities to receive institutional care in an ICF/IID. The purpose of these services is to enable individuals to live in a home or community setting rather than in an institution. HCBS includes non-medical supportive services, such as assistance performing activities of daily living (e.g., eating, toileting, etc.), which are comparable to PA services. HCBS also include skilled nursing services that, if provided by a TennCare MCO, would be classified as PDN services. TennCare contracts with the Tennessee Department of Intellectual & Developmental Disabilities to administer these services under federal waivers authorized by Section 1915(c) of the Social Security Act, 42 U.S.C. § 1396n, and Tenn. Comp. R. & Regs. §§ 1200-13-13-01-.25, -.28, -.29. These programs are known collectively as the “DIDD Waiver.”

31. DIDD Waiver services are provided pursuant to a written plan of care, known as an independent support plan (ISP), to “individuals with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of

care provided in ... [an ICF/IID].” 42 U.S.C. § 1396n(c)(1). The plan of care is developed in consultation with the individual and their family, the individual’s treating physician, and health care and support professionals, and is based on an independent, individualized evaluation of the person’s needs, preferences, and capacities, which is reviewed at least annually and updated as necessary. 42 U.S.C. § 1396n(i)(1)(E)-(H).

32. TennCare must inform DIDD Waiver enrollees of the alternatives to traditional, long-term institutional care, and of their right to choose among those alternatives. 42 U.S.C. § 1396n(c)(2)(C). An enrollee must be “[g]iven the choice of either institutional or home and community-based services.” 42 C.F.R. § 441.302(d)(2). In order for that choice to be meaningful, the offer of HCBS must provide an alternative to institutional care that is actually available and that fulfills an individual’s medical needs. *Waskul v. Washtenaw Cty. Cmty. Mental Health*, 979 F.3d 426, 457 (6th Cir. 2020).

33. During the 2021 session of the Tennessee General Assembly, legislation was enacted that requires agencies that contract to provide services through the DIDD Waiver to pay an hourly wage for direct care professionals, which includes personal attendants, of at least twelve dollars and fifty cents (\$12.50) per hour, effective July 1, 2021. Tenn. Code Ann. § 33-1-309(d)(1) (amended by Tenn. Pub. Ch. 576). However, the State left in place rates for other DIDD Waiver services that remain well below the rates that TennCare pays for the provision of those services to other TennCare enrollees. Many agencies therefore remain unwilling to contract with DIDD, and the DIDD Waiver provider network remains inadequate to meet the care needs of its enrollees.

34. The public policy of the State of Tennessee with regard to the provision of long-term services and supports, including those covered by TennCare, for individuals with disabilities, is set out in Tenn. Code Ann. § 71-5-1402(e) and (f), which require that:

- (e) The long-term care system shall recognize and value the critical role of the family and other caregivers in meeting the needs of the elderly and people with physical disabilities and shall offer services such as caregiver training, adult daycare and respite that wrap around the natural support network in order to keep it in place, thereby delaying or preventing the need for more expensive institutional care.
- (f) The long-term care system shall deliver needed supports and services in the most integrated setting appropriate and cost-effective way possible in order to utilize available funding to serve as many people as possible in home and community settings.

35. In guidance issued to state Medicaid agencies on January 10, 2001, the Health Care Financing Administration (as CMS was then called), explained the complementary roles of EPSDT and HCBS waivers authorized under Section 1915(c):

[A] child's enrollment in an HCBS waiver cannot be used to deny, delay, or limit access to medically necessary services that are required to be available to all Medicaid-eligible children under federal EPSDT rules.

...

Children who are enrolled in the HCBS waiver must also be afforded access to the full panoply of EPSDT services....

Therefore, under EPSDT requirements, a State must cover any medically necessary services that could be part of the basic Medicaid benefit if the State elected the broadest benefits permitted under federal law (not including HCBS services, which are not a basic Medicaid benefit). Therefore, EPSDT must include access to case management, *home health, and personal care services* to the extent coverable under federal law.

(Exhibit 2, pp. 10-11)²

36. States are also required to provide an opportunity for a fair hearing before the State agency to any individual whose claim for medical assistance is denied or is not acted upon with reasonable promptness. 42 U.S.C. § 1396a(a)(3). The fair hearing requirement includes, among other thing, an obligation to provide timely notice and a full opportunity for the beneficiary to present her case to an impartial decisionmaker. The state Medicaid agency must render a

² The letter is available at <https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd011001a.pdf> and is filed as Exhibit 2 to this complaint.

decision within 90 days of receiving an appeal and must take prompt corrective action as necessary to implement a hearing decision in the appellant's favor. 42 C.F.R. §§ 431.244(f)(1), .246.

Plaintiff M.A.C.

37. M.A.C. is 17 years old and lives in Clarksville, Tennessee with her father and mother, M.E.C. Her parents began caring for her in 2011, when the Tennessee Department of Children's Services ("DCS") placed M.A.C. and her siblings with them as foster parents. Then in 2014, her parents formally adopted M.A.C. when she was 10 years old.

38. M.A.C. is enrolled in TennCare, and her assigned MCO is Amerigroup. The severity of her intellectual and developmental disabilities and related medical needs are so great that she qualifies for institutionalization in an ICF/IID. For that reason, she also qualifies for enrollment in the DIDD Waiver since she was enrolled in 2005.

39. M.A.C.'s current ISP, which was approved by DIDD on January 13, 2021, documents that M.A.C. loves going to school and attending summer programs. (Exhibit 3 to this complaint, p. 2). She enjoys spending time with her family and watching TV with her siblings. *Id.* M.A.C. likes being around friends her age. *Id.*, p. 3. M.A.C. also likes to attend church and being active in the community. *Id.*

40. The ISP describes M.A.C.'s medical diagnoses as follows:

Congenital Hydrocephalus, Cerebral Palsy, and Septo-Optic dysplasia; Drug (Steroid) induced diabetes Mellitus With Hyperglycemia; Hx of Upper Gastrointestinal Bleed; Gastroesophageal Reflux Disease (GERD), Seizure Disorder (Cms/Hcc), Dysphagia, Autoimmune Hepatitis; Slow Transit Constipation, Hypertension, Allergic Rhinitis: History of Back Surgery 2015

(*Id.*, p. 9.)

41. M.A.C. is nonverbal, non-ambulatory, and can never be left alone, much of that time she requires direct care by a professional nurse. She requires skilled nursing care for services

such as G-tube feeding, medication by G-tube, blood sugar checks and insulin injections prior to feedings, suctioning and seizure intervention. M.A.C. also requires total assistance with her activities of daily living (e.g., toileting, bathing, etc.).

42. For many years, M.A.C. received 80 hours per week of PDN services. Approximately two years ago, when M.A.C. was 15 years old, her MCO cut coverage of her PDN services from 80 hours to 50 hours per week. Thirty hours of PA care was then requested and authorized through M.A.C.'s DIDD waiver. However, the provider was consistently unable to meet M.A.C.'s care needs and missed frequent shifts. On July 17, 2020, concerned that the hours of care M.A.C. received were insufficient to meet her needs, M.A.C.'s treating physician ordered that her PDN hours be restored to 80 hours. The MCO refused to increase the PDN hours. In October 2020, the provider stopped providing any services, and DIDD was unable to locate an alternative provider.

43. On November 20, 2020, M.A.C.'s attorney from the Tennessee Justice Center (TJC) wrote a letter to TennCare General Counsel explaining M.A.C.'s need for the services DIDD was not providing and that she should receive these medically necessary services under EPSDT. TennCare rebuffed the request and suggested that TJC encourage M.A.C.'s family to engage with her ISP, DIDD, providers, and MCO, to resolve the unmet care problem, though M.E.C. has always been active in M.A.C.'s meetings to plan and coordinate her care and supports.

44. With the help of counsel from the TJC, M.A.C.'s parents appealed TennCare's refusal to cover 80 hours of PDN care as ordered by her physician. Following an administrative hearing, a state administrative law judge (ALJ) issued a ruling on January 21, 2021. (Exhibit 4 to this complaint.) The ALJ ruled that M.A.C.'s MCO need only provide 50 hours of PDN but found that the DIDD Waiver should be providing M.A.C. the 30 hours per week of PA services, as

provided in her approved ISP at the time. The order became final on February 16, 2021. TennCare has taken no corrective action to provide M.A.C. the PA services the ALJ ruled she should be receiving.

45. DIDD acknowledges that M.A.C. needed more hours of coverage and in M.A.C.'s most recent ISP, authorized 34 hours per week of PA care, to complement the 50 hours of PDN covered by the MCO. (Exhibit 3 to this complaint, p. 3.) TennCare's practice of paying lower rates for home care provided to DIDD enrollees, has deterred, and continues to deter, agencies from contracting with DIDD. As a result, since October 2020, DIDD has failed to provide any of the hours of PA care as prescribed in M.A.C.'s ISP.

46. M.A.C.'s independent support coordinator (ISC) has worked since October 2020 to find other providers who can meet M.A.C.'s need for PA services, but due to the inadequacy of the DIDD provider network has been unsuccessful.

47. On April 9, 2021, M.A.C.'s attorney at the TJC wrote to the Office of the Tennessee Attorney General on M.A.C.'s behalf, documenting TennCare's failure to meet M.A.C.'s care needs. Neither the Attorney General's Office nor TennCare responded.

48. To this day, M.A.C. remains without the PA services TennCare, DIDD, and a state ALJ all concede she requires. Instead, M.E.C. covers all the missed hours in addition to caring for other family members, including her elderly mother. This has negatively impacted M.A.C.'s quality of life as her mother is now forced to be her full time PA. M.E.C. is unable to engage with her daughter and do activities that M.A.C. was used to doing, like her activity cards and word exercises. M.A.C.'s speech therapist has noted a recent decline in M.A.C.'s communication abilities.

49. Without a PA, M.A.C. is also unable to engage with the community. She goes on less outings and frequently misses church. During church, M.A.C. must stay at home with another family member because her mother, as the church's praise leader, and father, as the church's assistant pastor, are active in the service and cannot safely bring M.A.C. to the church without assistance from a PA.

50. In late 2020 M.E.C. hurt her back and shoulder when lifting M.A.C.. She continues to experience pain and discomfort. If M.E.C. becomes unable to care for her daughter, M.A.C. faces a significant risk of institutionalization.

51. If M.A.C. is institutionalized in an ICF/IID, TennCare will pay the institution for the full cost of whatever care M.A.C. requires to maintain her health and safety. TennCare's refusal to provide her medically necessary PA care denies her the ability to live safely in the community with her family. Defendants deny her a meaningful choice between receiving the care she requires at home in the community and the institutional setting of an ICF/IID.

Plaintiff Scarlet Burk

52. Scarlet is 19 years old and lives in Fayetteville, Tennessee, with her mother, Felicia Burk, her siblings, and nieces and nephews. Ms. Burk, a special education teacher, adopted Scarlet and her brother after their biological mother was killed in a car accident.

53. Scarlet is enrolled in TennCare, and her assigned MCO is *TennCareSelect*. The severity of her intellectual and developmental disabilities and related medical needs are so great that she has qualified for institutionalization in an ICF/IID. Because of this, Scarlet qualifies for the DIDD waiver since she was enrolled in 2005.

54. Some of the things that are most important to Scarlet are being with her family, her care staff, playing in the bathtub and with shoes, having her hair and nails done, and swimming. (Exhibit 5 to this complaint, p. 3.)

55. Scarlet's current ISP, which was approved by DIDD, on May 17, 2021, describes her medical diagnoses as follows:

Autism, Intellectual Disability, ADHD, [Attention Deficit Hyperactivity Disorder], Erythema Nodosum. She also has Impulse Control Disorder, probable Bi-Polar Disorder, Sleep Disorder, Emotional disturbance with multi-handicapping conditions and a feeding disorder.

Id., p. 10. Scarlet has also been diagnosed with abnormality of the aortic valve and has had several surgeries. *Id.*, p. 10-11.

56. Scarlet can engage in self-injurious behaviors such as pulling out her hair and hitting herself repeatedly in the face. *Id.*, p. 5. She may try to grab items on others, such as glasses or jewelry, hurting the person in the process. *Id.* Scarlet also elopes and may enter a neighbor's car or home and may take items and destroy property. *Id.*, p. 6. She has locked herself in rooms, stripped, and hidden in the bathtub. *Id.*

57. Because of Scarlet's risk for elopement, self-injurious behavior, and possible injury to others, Scarlet needs 24/7 care to provide for her safety. Scarlet's current ISP repeatedly directs PA supports to provide total assistance to complete all functional/daily activities. *Id.*, p. 5-13.

58. Doctors prescribe 24/7 PA care as medically necessary to protect Scarlet from the constant threat of serious self-harm or harm to others. She is physically strong, which makes her inability to control her behaviors even more dangerous.

59. As a child under the age of 21, Scarlet is entitled to EPSDT services. Those services include PA services as necessary "for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level." 42 U.S.C. § 1396d(a)(7) and (8)

and 42 U.S.C. § 1396d(r); 42 C.F.R. § 440.167; Tenn. Comp. R. & Regs. R. Rule 1200-13-13-.01(92).

60. In 2011, Scarlet's physician prescribed 24/7 PA services for her, to be provided by her MCO, *TennCareSelect*. As a child, Scarlet was entitled to receive all medically necessary Medicaid services (including PA services) as EPSDT benefits, with the DIDD Waiver supplementing *TennCare* by providing any other types of services that are not covered as a Medicaid benefit. (Exhibit 2 to this complaint.) *TennCareSelect* nonetheless refused the order, on the grounds that the DIDD Waiver was already providing PA services 17 hours per day, claiming that relieved it of responsibility for providing the additional hours that had been prescribed. (Exhibit 6 to this complaint.)

61. Ms. Burk tried to get the prescribed PA services for her daughter through the DIDD waiver. However, the DIDD waiver limits coverage of PA care to 215 hours per month, without regard to the enrollee's needs.

62. In March 2019, April 2020, and February 2021, Scarlet's doctors repeatedly ordered 24/7 PA care. In response to DIDD's denial of the April 2020 request, again capping her approved PA hours at 215 per month, TJC assisted Ms. Burk in appealing the decision, invoking *TennCare*'s obligation to provide the care as medically necessary as an EPSDT service.

63. There was no communication from DIDD to Scarlet's MCO asking *TennCare* to cover the care as medically necessary. *TennCare* did not provide Scarlet a hearing and finally, after 147 days, peremptorily closed the appeal. The dismissal relied upon the hourly cap on PA care in the DIDD Waiver rules, ignoring the appeal's effort to invoke *TennCare*'s EPSDT obligations.

64. On October 14, 2020, TJC wrote to *TennCare*'s General Counsel citing EPSDT and noting the obligation of Scarlet's MCO to provide all PA hours as medically necessary.

65. On November 11, 2020, TennCare's General Counsel responded that Section 1915(c) waiver recipients are not entitled to EPSDT coverage for services provided under the waiver, that Ms. Burk should submit a formal request to Scarlet's MCO but that TennCare reached out to Ms. Burk's MCO to determine if the additional services is appropriate.

66. Ms. Burk did not receive any notices or communication from Scarlet's MCO regarding this assessment.

67. TennCare is not providing Scarlet even the limited hours of PA care per month that are approved for coverage through the DIDD Waiver. Because of the inadequacy of its provider network, the DIDD Waiver is providing Scarlet only 100-120 hours of the 215 hours ordered in her ISP.

68. On April 9, 2021, Scarlet's attorney at the TJC wrote to the Office of the Tennessee Attorney General on Scarlet's behalf, documenting TennCare's failure to meet her care needs. Neither the Attorney General's Office nor TennCare responded.

69. TennCare's continuing refusal to cover 24/7 PA care for Scarlet as medically necessary repeatedly puts Scarlet at risk of serious injury and hospitalizations for Ms. Burk and leaves Scarlet at ongoing risk of serious harm.

70. Beginning on June 2, 2021, Ms. Burk was hospitalized for 5 days because she entered a Hyperosmolar Hyperglycemic State which is a condition that develops due to high blood pressure and blood sugar. Her doctors state that one of the biggest concerns to her health is her stress regarding Scarlet's care and wellbeing. If Ms. Burk becomes unable to care for her daughter, there will be no choice but to institutionalize her.

71. If Ms. Burk institutionalizes her daughter in an ICF/IID, TennCare will pay the institution for the full cost of whatever care Scarlet requires to maintain her health and safety. By

contrast, TennCare's refusal to provide her medically necessary PA care denies her the ability to live safely in the community with her family. Defendants thus deny her a meaningful choice between receiving the care she requires at home in the community and the institutional setting of an ICF/IID.

Plaintiff Binta Barrow

72. Binta Barrow is a 25-year-old woman who lives with her mother, Sadiatou Jallow, in Knoxville, Tennessee. At birth Ms. Jallow was told that Binta had only a few years to live, but because of Ms. Jallow's constant attention to her daughter's care, she has outlived her prognosis by over 20 years.

73. Binta is enrolled in TennCare and is assigned to TennCareSelect as her TennCare health plan. Because of the severity of her intellectual and developmental disabilities, she would qualify to be placed in an ICF/IDD facility. For that reason, she qualifies for the DIDD waiver to receive services in her home. She has been enrolled in the DIDD Waiver since 2006.

74. Binta's current ISP which was approved by DIDD, on February 3, 2021, relays that Binta has a good sense of humor and often laughs at things she finds funny. (Exhibit 7 to this complaint, p. 2). She enjoys listening to music and watching television, particularly "Family Feud" and "Judge Judy." *Id.*, p. 3. She also enjoys playing with her interactive toys and listening to her staff sing or read. *Id.*, p. 2-3. It is very important to Binta to stay at home with her mother and to interact with familiar people like her staff. *Id.*, p. 3, 13.

75. Binta's ISP describes her medical diagnoses as follows:

Dandy-Walker Syndrome Hydrocephalus, Cerebral dysgenesis, Seizure disorder/Lennox-Gestaut syndrome, Cortical blindness, Reactive airway disease/Localized edema, GERD, Cerebral palsy, Dysphagia, Ileus, Pseudo obstruction, Severe psychomotor delay, Chronic constipation, Scoliosis, Lower extremity contractures, Allergic rhinitis, and Chronic sialadenitis.

Id., p. 9.

76. Binta is blind, nonverbal, has limited use of her arms and needs total care with all daily functions. She also requires skilled nursing care, such as medication administration and feeding through her G-tube, suctioning and seizure intervention. Binta's physicians have prescribed 24/7 bedside care for her through a combination of certified nurse assistant (CNA) and private duty nursing (PDN) services to be provided by TennCareSelect, and PA services covered by the DIDD Waiver.

77. In 2011, TennCare notified Binta's mother that she should place Binta in an ICF/IID to enable her to continue receiving the continuous bedside care she required. Her family refused and intervened in a federal lawsuit to enforce her rights under the Americans with Disabilities Act. The lawsuit concluded with a confidential settlement. TennCare continued to provide Binta with 24/7 care.

78. For more than a decade, TennCare and DIDD have failed to adequately staff the shifts of coverage that TennCare acknowledges Binta needs. This has resulted in both Ms. Jallow and Binta being hospitalized on different occasions.

79. Ms. Jallow has a serious heart disease and is unable to lift Binta to move her. In January 2018, when one of many missed shifts left Ms. Jallow to try to care for her daughter by herself, the exertion exacerbated her heart condition, requiring Ms. Jallow's emergency hospitalization for several days.

80. On August 2, 2020, Binta was hospitalized due to aspiration pneumonia. Her health was in such jeopardy that the hospital staff doubted she would survive. Fortunately, she recovered and was sent home with oxygen treatment that required even more careful monitoring than she

was already receiving. However, she continues to experience frequent missed shifts and dangerous gaps in care due to DIDD's inability to staff her hours.

81. That same month, under the physical and emotional strain of trying to care for her daughter alone during the many shifts that were unstaffed, Ms. Jallow's heart disease worsened, and her physician increased the dosage of her heart medication.

82. As ordered by her prescribing physician and provided in Binta's approved ISP, the DIDD Waiver should currently be providing 81 hours per week of PA care for Binta.

83. Beginning May 14, 2021, one of the caregivers providing PA care stopped providing care for Binta. A new provider took over the services but is consistently unable to staff 40 hours per week of Binta's care.

84. The DIDD waiver administrators have been aware of this impending reduction since mid-April but the inadequacy of DIDD's provider network has made it impossible for Binta to receive the full hours of PA care that she needs and is authorized to receive.

85. Binta has not received any notices from TennCare, DIDD, or the provider agency stating that TennCare is unable to provide her full 81 hours, and TennCare has not provided her with the opportunity to appeal. Ms. Jallow provides consistent updates to Binta's PA service provider, ISC, and MCO case manager on all of Binta's missed shifts.

86. On May 6, 2021, Binta's attorney at the TJC wrote to the Office of the Tennessee Attorney General on Binta's behalf, documenting TennCare's failure to meet her care needs. Neither the Attorney General's Office nor TennCare responded.

87. Binta's independent support coordinator (ISC), who is responsible for coordinating her DIDD Waiver services, has worked to find other providers, but because of the lack of home health agencies willing to contract with DIDD, has had no success.

88. On May 2, 2021, Ms. Jallow experienced rapid heart palpations. She was admitted to the hospital, where she was diagnosed with atrial fibrillation.

89. Binta's ISP notes that the PA hours provided by DIDD are needed because Ms. Jallow's health condition does not allow her to care for Binta safely for extended periods of time. *Id.*, p. 5. If Ms. Jallow becomes unable to care for her daughter, there will be no choice but to institutionalize her.

90. If Binta is institutionalized in an ICF/IID, TennCare will pay the institution for the full cost of whatever care Binta requires to maintain her health and safety. By contrast, TennCare's refusal to provide her medically necessary PA care denies her the ability to live safely in the community with her family. Defendants deny Binta a meaningful choice between receiving the care she requires at home in the community and the institutional setting of an ICF/IID.

Plaintiff Jay Bryant

91. Jay R. Bryant is 32 years old and lives with his mother, Ms. Ann R. Bryant, in Mohawk, Tennessee. Jay's sister, Ms. Drama Bryant provides much of his care and lives just next door. Ms. Bryant is a trained personal attendant.

92. Jay is enrolled in TennCare and his assigned MCO is BlueCare. The severity of his intellectual and developmental disabilities and related medical needs are so great that he qualifies for institutionalization in an ICF/IID. For that reason, he also qualifies for enrollment in the DIDD Waiver, and has been enrolled in the Waiver since 2005.

93. Jay enjoys music of all kinds including classical and gospel. (Exhibit 8 to this complaint, p. 2.) He also likes watching television and using his red nylon fabric as a sensory item to feel safer. *Id.*, p. 2, 9. Jay's ISP emphasizes that his mother, sister, and father are very important

to him. *Id.*, p. 5. He loves to spend time with them and feels most safe and comfortable when his mother and sister are present. *Id.*

94. Jay's current ISP, which was approved by DIDD on May 5, 2021, describes his medical diagnoses as follows:

Seizures, Pica, Psoriasis, Vitamin deficiency, seasonal allergies, generalized pain, GERD [Gastroesophageal reflux disease], and Eczema.

Id., p. 6.

95. Jay must always be within line of sight to his DIDD provider or family member due to his frequent and intense self-injurious and aggressive behaviors and attempts to eat inedible items like grass, dirt, and rocks. *Id.*, p. 3-5. His current ISP directs PA supports to complete tasks for all areas of daily living such as using the toilet and preventing injury to himself and others. *Id.* Jay also needs PA supports to prevent fecal digging.

96. Jay's ISP notes that PA services are needed, because his 69-year-old mother is incapable of meeting his needs due to her own serious health problems, including high blood pressure, back pain related to an injury, and early dementia. *Id.*, p. 2. Jay's mother is also at risk of falling and in one incident was so badly hurt that emergency medical services needed to be called. Luckily, Jay's sister happened to be present at the time.

97. Previously Jay received two-on-one 24/7 PA care through the DIDD waiver. In 2010, TennCare attempted to reduce his PA hours multiple times but quickly reinstated the hours due to his aggressive and self-injurious behavior.

98. In 2011, TennCare notified Jay's family that his PA care would be reduced and capped at 50 hours per week, and suggested that he should be placed ICF/IID to continue receiving the continuous care he required. The family refused and intervened in a federal lawsuit to enforce his rights under the Americans with Disabilities Act. The lawsuit concluded with a confidential

settlement. From the conclusion of that lawsuit until the present, TennCare has authorized 215 hours of PA care per month.

99. Each year, Jay's ISC submits the request for 215 hours of PA services per month and the hours are authorized by TennCare. Jay's ISC also requested wraparound in-home day services provided by a Direct Support Professional (DSP). DIDD approved the request, and his ISP promises him 122 hours per month of wraparound in-home day services.

100. DIDD has not provided any of Jay's approved wraparound in-home day services since March of 2020 and has only provided 184 hours per month of his PA services. These hours are filled only because his sister is hired to provide those services and also works overtime. Due to the inadequacy of the DIDD provider network, Jay is not receiving 151 hours of his authorized care per month.

101. On November 16, 2020, TJC assisted the family in filing a medical services appeal for the reduction in Jay's services. It has been more than 90 days and DIDD has not provided Jay an opportunity for a hearing or taken corrective action to remedy the ongoing denial of medically necessary care.

102. On April 9, 2021, Jay's attorney at the TJC wrote to the Office of the Tennessee Attorney General on Jay's behalf, documenting TennCare's failure to meet his care needs. Neither the Attorney General's Office nor TennCare responded.

103. Even before the onset of the coronavirus pandemic, TennCare's failure to staff Jay's DIDD Waiver services had resulted in his isolation and reduced his quality of life. The failure has made it impossible for Jay to safely go outside his home to interact with the community since January 2020.

104. Since he has been unable to receive the prescribed level of staffing, Jay has missed receiving prescribed medications, has been unable to make doctor appointments, and has experienced more seizures. Jay is also at a heightened risk of falling and, without adequate staff to intervene or assist, the risk of serious injury is increased.

105. On July 1, 2021, Adult Protective Services visited Jay's family because it had received a report that he was endangered by the failure to receive the care he requires. If Jay continues to experience missed shifts, he will no longer be able to safely stay in his home and there will be no choice but to institutionalize him.

106. If Jay is institutionalized in an ICF/IID, TennCare will pay the institution for the full cost of whatever care Jay requires to maintain his health and safety. By contrast, TennCare's refusal to provide his medically necessary PA care denies him the ability to live safely in the community with his family. Defendants deny Jay a meaningful choice between receiving the care he requires at home in the community or in the institutional setting of an ICF/IID.

Plaintiff Amanda Casey

107. Amanda Casey is a 41-year-old woman who lives with her stepfather and mother, Ronda Coggins, in Telford, Tennessee.

108. Amanda is enrolled in TennCare and is assigned to *TennCareSelect* as her TennCare health plan. Because of the severity of her intellectual and developmental disabilities, she would qualify to be placed in an ICF/IDD facility. For that reason, she qualifies for the DIDD waiver to receive services in her home. She has been enrolled in the DIDD Waiver since 1987.

109. Amanda's current ISP, which was approved by DIDD on November 30, 2020, explains that staying at home with her mother and stepfather are most important to her. (Exhibit 9

to this complaint, p. 2). Amanda loves being around family, bubble baths, and snuggling. Amanda enjoys spending time with familiar supporters and responds to familiar voices. *Id.*, p. 2-3.

110. Amanda's ISP describes her medical diagnoses as follows:

Seizure, Microcephaly, Cerebral palsy, spastic quadriplegia, Lennox-Gastaut syndrome.

Id., p. 10.

111. Amanda is also diagnosed with Cortical blindness, West Syndrome, Seizure disorder and Catamenial epilepsy. She experiences continuous Nystagmoid movement and has bilateral ovarian cysts. Amanda also has an anxiety disorder that is post-traumatic in nature due to past abuse by a nursing caretaker.

112. Amanda can experience 100-120 seizures per month and is at risk of falling, choking, or aspirating. Because of her seizures, her oxygen level may drop to dangerously low levels and her mother or nurse must supply her oxygen. She must be in the line of sight of a supporter at all times. When afflicted by seizure activity, she can stay awake for three to four consecutive days. If she is in a confined space like the bath, and experiences an episode, she must be quickly lifted out and placed in a safe space. Amanda's physicians have prescribed 24/7 care for her through a combination of private duty nursing (PDN) services to be provided by TennCareSelect and PA services covered by the DIDD Waiver.

113. In 2011, TennCare notified Amanda's parents that her PA care would be capped at 215 hours per month if she stayed at home and suggested that they place her in an ICF/IID to enable her to continue receiving the continuous care she required. The family refused and filed a federal lawsuit to enforce her rights under the Americans with Disabilities Act. The lawsuit concluded with a confidential settlement. TennCare has continued to provide Amanda with 24/7

care. However, Amanda has continuously experienced missed shifts with a notable increase in missed shifts beginning in December 2020.

114. As ordered by her prescribing physician and authorized in Amanda's approved ISP, the DIDD Waiver should currently be providing Amanda 84 hours per week of two-on-one PA care and 83 hours of single staff PA care per week, for a total of 251 hours per week of PA care. (Exhibit 10 to this complaint).

115. In a notice dated February 5, 2021, DIDD stated that Amanda's PA provider had decided to end its contract with DIDD, but that there would be no interruption of the supports and services that Amanda receives while a new provider is being identified. *Id.*, p. 2. Amanda was still experiencing missed shifts at the time of this letter.

116. In March 2021, Amanda began experiencing a marked increase in missed shifts. Since May 2021 Amanda has only been receiving about 36 hours per week of PA care, instead of the 251 hours that are approved.

117. Amanda has not received any notices from TennCare, DIDD, or the provider stating that they are unable or unwilling to provide her full 251 hours, and TennCare has not provided her with the opportunity to appeal the reduction in services. Her family has had no recourse to remedy the ongoing denial of care that threatens her health and safety.

118. On June 3, 2021, Ms. Coggins sent a letter explaining her daughter's life-threatening situation to the White House, Vice President, Governor Bill Lee, Senator Marsha Blackburn, Representative Diana Harshbarger, and State Representative Rebecca Alexander. Ms. Coggins received a letter from Governor Bill Lee and the offices of Marsha Blackburn and Rebecca Alexander have corresponded with Ms. Coggins, but Amanda continues to experience

215 hours of missed shifts per week for her PA care. She has still heard nothing from TennCare, DIDD or any state contractor, nor has she been offered an appeal to contest the reduction.

119. Amanda's ISC, who is responsible for coordinating her DIDD Waiver services, has worked to find other providers, but, because of the inadequacy of the DIDD provider network, has had no success.

120. Amanda's mother, Ms. Coggins, who is 67 years old, must cover all of Amanda's missed shifts in care, including night shifts. Amanda can experience life threatening seizure activity at any time and her seizures put her at risk of falling. If Ms. Coggins becomes unable to care for her daughter, Amanda will not be able to remain safely at home and there will be no choice but to institutionalize her.

121. If Amanda is institutionalized in an ICF/IID, TennCare will pay the institution for the full cost of whatever care Amanda requires to maintain her health and safety. By contrast, TennCare's refusal to provide her medically necessary PA care denies her the ability to live safely in the community with her family. Defendants deny Amanda a meaningful choice between receiving the care she requires at home in the community and the institutional setting of an ICF/IID.

CAUSES OF ACTION

Count I: Violation of 42 U.S.C. § 1396n(c)(2)(A)

122. Plaintiffs incorporate all prior paragraphs.

123. Section 1915(c) of the Medicaid Act, 42 U.S.C. § 1396n(c)(2)(A), requires that in administering a waiver program providing HCBS to individuals with intellectual disabilities, a state must ensure that:

necessary safeguards . . . have been taken to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services;

124. Under this statute, Defendants are required to provide “assurance that services are provided in home and community based settings, as specified in [42 C.F.R.] § 441.301(c)(4).” 42 C.F.R. § 441.302(a)(5). Section 441.301(c)(4) requires that home and community based settings (1) “support[] full access of individuals receiving [services] to the greater community, including opportunities to . . . engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving [services],” *id.* § 441.301(c)(4)(i); (2) “optimize[], but . . . not regiment, individual initiative, autonomy, and independence in making life choices,” *id.* § 441.301(c)(4)(iv); and (3) “facilitate[] individual choice regarding services and supports, and who provides them,” *id.* § 441.301(c)(4)(v).

125. The requirements of Section 1396n(c)(2)(A) are clearly intended to protect the health and welfare of Medicaid recipients, to confer rights on such recipients, and to impose a mandatory duty on the State. This mandatory duty is neither vague nor amorphous; rather, it is an unambiguous directive. The rights established under 42 U.S.C. § 1396n(c)(2)(A) are enforceable by Plaintiffs pursuant to 42 U.S.C. § 1983, under which they bring this claim.

126. The Defendants, acting under color of state law, are not meeting the requirements of Section 1396n(c)(2)(A), as they are not allowing Plaintiffs the opportunity to receive medically necessary services in the community, not optimizing Plaintiffs’ independence in making life choices, and not facilitating Plaintiffs’ individual choice regarding services and who provides them. By failing to provide Plaintiffs the level of PA care they require to live safely in their homes while offering the requisite level of such care if they agree to be institutionalized in an ICF/IID, the Defendants have deprived, and continue to deprive, Plaintiffs of their rights to necessary safeguards under 42 U.S.C. § 1396n(c)(2)(A).

127. As a result of this deprivation, Plaintiffs have suffered, and continue to suffer, harm in the form of preventable suffering, and they are at risk of suffering irreparable injury to their health.

Count II: Violation of 42 U.S.C. § 1396n(c)(2)(C)

128. Plaintiffs incorporates all prior paragraphs.

129. Section 1915(c) of the Medicaid Act also requires that in administering a waiver program providing HCBS to individuals with intellectual disabilities, a state must ensure that:

such individuals who are determined to be likely to require the level of care provided in a[n] ... intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of ... services in an intermediate care facility for the mentally retarded;

42 U.S.C. § 1396n(c)(2)(C).

130. Under this statute, Defendants are required to ensure that Plaintiffs are “[g]iven the choice of either institutional or home and community-based services.” 42 C.F.R. § 441.302(d)(2).

131. The requirements of Section 1396n(c)(2)(C) are clearly intended to protect the health and welfare of Medicaid recipients, to confer rights on such recipients, and to impose a mandatory duty on the State. This mandatory duty is neither vague nor amorphous; rather, it is an unambiguous directive. The right established under 42 U.S.C. § 1396n(c)(2)(C) is enforceable by Plaintiffs pursuant to 42 U.S.C. § 1983, under which he brings this claim.

132. The Defendants, acting under color of state law, fail or refuse to provide Plaintiffs the level of care needed in their home that is prescribed by their approved Individual Support Plan, knowing that they cannot safely remain at home without the prescribed level of care. By only offering Plaintiffs the level of care they need if they agree to be institutionalized in an ICF/IID, the

Defendants have deprived, and continue to deprive, Plaintiffs of a meaningful choice between institutional or home and community-based services, in violation of 42 U.S.C. § 1396n(c)(2)(C).

133. As a result of this deprivation, Plaintiffs have suffered, and continue to suffer, harm in the form of preventable suffering, and they are at risk of being subjected to involuntary institutionalization in an ICF/IID in order to get the care they need.

Count III: Unlawful Discrimination Under the Americans with Disabilities Act

134. Plaintiffs incorporate all prior paragraphs.

135. Plaintiffs are each a “qualified individual with a disability” as defined in 42 U.S.C. § 12131(2). They are individuals with a disability who meet the essential eligibility requirements for the TennCare program with reasonable modification to the rules, policies, and practices of that program.

136. The defendant agency, DFA, including its Division of TennCare, is a “public entity” for the purposes of Title II of the Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12131(1), and the federal regulations promulgated thereunder.

137. Title II of the ADA provides that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such an entity. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(a).

138. By failing to contract with sufficient providers to meet the service needs of individuals with intellectual disabilities, including the Plaintiffs, who receive those services through the DIDD Waiver, while offering better terms to providers the same types of services to other TennCare enrollees, the Defendants have violated, and continue to violate, the Plaintiffs’ rights under 42 U.S.C. § 12132 and the following implementing regulations:

- a) 28 C.F.R. § 35.130(7)(i), which requires that:

A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.

- b) 28 C.F.R. § 35.130(8), which provides that:

A public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.

139. By historically paying lower rates for services for individuals with intellectual disabilities enrolled in the DIDD Waiver than it has paid for the same care provided to any other TennCare enrollee, Defendants have deterred agencies from contracting with DIDD to meet the care needs of DIDD Waiver enrollees. The Defendants have thus discriminated, and continue to discriminate, against Plaintiffs by reason of their intellectual disabilities.

140. Defendants could make a reasonable accommodation by directing Plaintiffs' MCOs to provide the care, or by otherwise ensuring that they receive the PA hours of care the Defendants have long determined that the Plaintiffs need.

Count IV: Unlawful Discrimination under Section 504 of the Rehabilitation Act

141. Plaintiffs incorporate all prior paragraphs.

142. Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, together with its implementing regulations, including 28 C.F.R. § 41.51(d) and 45 C.F.R. Part 84, Subpart A, and the right of action granted by 29 U.S.C. § 794a, are all construed *in pari materia* with the ADA.

143. Section 504 of the Rehabilitation Act provides that:

No otherwise qualified individual with a disability in the United States, as defined in section 7(20) [29 U.S.C. § 705(20)], shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be

subjected to discrimination under any program or activity receiving Federal financial assistance...

29 U.S.C. § 794(a); 45 C.F.R. § 84.4(a).

144. Plaintiffs are each a “qualified individual with a disability” within the meaning of 29 U.S.C. § 794(a) and a “qualified handicapped person” under 45 C.F.R. § 84.3(l).

145. The TennCare program administered by the Defendants is a “program or activity receiving Federal financial assistance” within the meaning of 29 U.S.C. § 794(a). By continuing to participate in the Medicaid program, and continuing to accept federal funding therefor, after enactment of 42 U.S.C. § 2000d-7, the State of Tennessee has waived its Eleventh Amendment immunity for claims under the Rehabilitation Act related to its conduct of the Medicaid program.

146. By historically paying lower rates for services for individuals with intellectual disabilities enrolled in the DIDD Waiver than it has paid for the same care provided to any other TennCare enrollee, Defendants have deterred agencies from contracting with DIDD, resulting in the maintenance of a provider network that is incapable of meeting the care needs of DIDD Waiver enrollees, including the Plaintiffs. Defendants have thus discriminated, and continue to discriminate, against Plaintiffs by reason of their intellectual disability. Such discrimination violates 29 U.S.C. § 794(a) and the following implementing regulations:

a) 45 C.F.R. § 84.4(b)(1)-(2), which requires that:

- (1) A recipient [of federal funding], in providing any aid, benefit, or service, may not, directly or through contractual, licensing, or other arrangements, on the basis of handicap:
 - i) ...
 - ii) Afford a qualified handicapped person an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others;
 - iii) Provide a qualified handicapped person with an aid, benefit, or service that is not as effective as that provided to others;
 - iv) Provide different or separate aid, benefits, or services to handicapped persons or to any class of handicapped persons

unless such action is necessary to provide qualified handicapped persons with aid, benefits, or services that are as effective as those provided to others;

...

vii) Otherwise limit a qualified handicapped person in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

- (2) For purposes of this part, aids, benefits, and services, to be equally effective, are not required to produce the identical result or level of achievement for handicapped and nonhandicapped persons, but must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement, in the most integrated setting appropriate to the person's needs.

b) 28 C.F.R. § 35.130(8), which provides that:

A public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.

147. By maintaining a provider network to serve enrollees in the DIDD Waiver that is inferior to the provider networks that serve all other TennCare enrollees, the Defendants violate 29 U.S.C. § 794 and implementing regulation 45 C.F.R. § 84.4(b)(4):

- (4) A recipient may not, directly or through contractual or other arrangements, utilize criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State.

Count V: Violation of the ADA's Integration Mandate

148. Plaintiffs incorporate all prior paragraphs.

149. Title II of the Americans with Disabilities Act (ADA) of 1990 (Title II), 42 U.S.C. § 12131 et seq., provides that "no qualified individual with a disability shall, by reason of such

disability, be excluded from participation in or be denied the benefits of the service, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132. Rights of action with respect to violations of Title II are expressly conferred by 42 U.S.C. § 12133.

150. A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R. § 35.130(d).

151. “[T]he most integrated setting appropriate to the needs of qualified individuals with disabilities mean[s] a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 592 (1999) (quoting 28 C.F.R. pt. 35, App. A, p. 450 (1998)) (internal quotation marks omitted).

152. The ADA prohibits both outright discrimination and “identified unjustified ‘segregation’ of persons with disabilities.” *Olmstead*, 527 U.S. at 600 (quoting § 12101(a)(2)).

153. “[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.” *Id.* at 600.

154. By failing to ensure that the Plaintiffs receive the PA care that TennCare has long determined they need—in their home—Defendants have placed the Plaintiffs at serious risk of forced institutionalization, in violation of the ADA’s integration mandate that public services be provided in the most integrated setting appropriate to the needs of a person with a disability.

155. Likewise, by making necessary care available to the Plaintiffs only in an ICF/IID institutional setting, while withholding that same necessary care in their own home and with their own family, the Defendants have violated, and continue to violate, the ADA’s integration mandate.

156. Defendants could make a reasonable accommodation by providing Plaintiffs with their approved PA hours, by directing Plaintiffs' MCOs to provide the care, or by otherwise ensuring that they receive the PA hours of care they have long determined he needs.

Count VI: Violation of the Integration Mandate of Section 504 of the Rehabilitation Act

157. Plaintiffs incorporate all prior paragraphs.

158. Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, together with its implementing regulations, including 28 C.F.R. § 41.51(d) and 45 C.F.R. § 84.4(b)(1)(vii), (2), and the right of action granted by 29 U.S.C. § 794a, are all construed *in pari materia* with the ADA with respect to *Olmstead* "most integrated setting" claims.

159. By failing to ensure the Plaintiffs receive the PA care that TennCare has long determined that they need—in their home—Defendants have placed the Plaintiffs at serious risk of forced institutionalization, in violation of Section 504 of the Rehabilitation Act.

160. By making necessary care available to the Plaintiffs only in an ICF/IID institutional setting, while withholding that same necessary care in their own home and with their own family, the Defendants have violated, and continue to violate, the integration mandate of Section 504 of the Rehabilitation Act. 45 C.F.R. § 84.4(b)(2).

Count VII: Violation of Medicaid EPSDT Guarantees under 42 U.S.C. § 1396d(r)

161. Plaintiffs incorporate all prior paragraphs.

162. The Medicaid Act, 42 U.S.C. § 1396d(a)(4) and 42 U.S.C. § 1396d(r), requires all state Medicaid programs to provide "early and periodic screening, diagnostic, and treatment services" for children under the age of 21, which includes:

necessary health care, diagnostic services, treatment, and other measures described in section 1905(a) [subsec. (a) of this section] to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan.

42 U.S.C. § 1396d(r).

163. Under 42 U.S.C. § 1396d(r)(5), (a)(7), home health care services such as PA are included as a covered service.

164. The Defendants have systematically failed, and continue to fail, to provide Plaintiffs M.A.C. and Scarlet Burk medically necessary PA services in violation of 42 U.S.C. § 1396d(r).

Count VIII: Violation of Due Process Under the Medicaid Act, 42 U.S.C. § 1396a(a)(3)

165. Plaintiffs incorporate all prior paragraphs,

166. The Medicaid Act requires all state Medicaid programs to “provide for granting an opportunity for a fair hearing before the state agency to any individual whose claim for medical assistance under the plan is denied or is not acted upon with reasonable promptness.” 42 U.S.C. § 1396a(a)(3).

167. The statute and its implementing rules require the Defendants to maintain a hearing system for Medicaid applicants and enrollees that meets the due process standards of *Goldberg v. Kelly*, 397 U.S. 254 (1970). 42 C.F.R. § 431.205(d).

168. Under this statute, Defendants are required to grant the opportunity of a hearing to any individual who requests it because she believes the Medicaid agency has taken an erroneous action denying or delaying benefits or services, including a change in the amount or type of benefits or services. 42 CFR 431.220(a)(1), (a)(1)(iv). The fair hearing must be before an impartial hearing officer, and the appellant must be able to bring witnesses, establish all pertinent facts and circumstances, and present argument without undue interference. 42 C.F.R. §§ 431.240 and 431.242. The Defendants must ensure that appeals are decided within 90 days from when they are

filed, and the Medicaid agency must take prompt corrective action to implement decisions favorable to the appellants. 42 C.F.R. §§ 431.244(f) and 431.246.

169. The Defendants have systematically failed, and continue to fail, to provide Plaintiffs an opportunity for a fair hearing regarding the delay, denial, or reduction of services in violation of 42 U.S.C. § 1396a(a)(3).

170. The requirements of Section 1396a(a)(3) are intended to protect the due process rights of Medicaid recipients, to confer rights on such recipients, and to impose a mandatory duty on the State to maintain a hearing system. This mandatory duty is neither vague nor amorphous; rather, it is an unambiguous directive. The right established under 42 U.S.C. § 1396a(a)(3) is enforceable by Plaintiffs pursuant to 42 U.S.C. § 1983, under which they bring this claim.

Count IX: Violation of Due Process Clause of the Fourteenth Amendment

171. Plaintiffs incorporate all prior paragraphs,

172. The Due Process Clause of the Fourteenth Amendment of the United States Constitution bars the state from depriving a person of her property, which includes TennCare services, without affording the individual advance notice and a fair opportunity to be heard.

173. The Defendants have deprived, and continue to deprive, the Plaintiffs of due process of law in violation of the Fourteenth Amendment by failing to provide a timely opportunity for a fair hearing and effective redress for the wrongful delay, denial, or reduction of medically necessary TennCare services to which the Plaintiffs are entitled.

174. Plaintiffs seek relief on this claim pursuant to 42 U.S.C. § 1983, which provides a cause of action to redress the deprivation of their constitutional rights by persons acting under color of state law.

REQUEST FOR RELIEF

For the unlawful harms described above, the Plaintiffs requests that this Court grant the following relief:

1. Enter a declaratory judgment, in accordance with 28 U.S.C. § 2201 and Fed. R. Civ. P. 57, declaring that the Defendants have violated and continue to violate Plaintiffs' rights under federal law, and declaring unlawful the Defendants' policies that have perpetrated those violations of Plaintiffs' rights.

2. Grant the Plaintiffs preliminary and permanent injunctive relief:

- a) prohibiting the Defendants from withholding medically necessary services in violation of the Medicaid Act and Americans with Disabilities Act;
- b) prohibiting the Defendants from implementing the unlawful policies complained of herein; and
- c) denying the Plaintiffs due process of law, in violation of the Medicaid Act and the Fourteenth Amendment to the United States Constitution.

3. Award reasonable attorneys' fees and costs as provided by 42 U.S.C. § 1988, 42 U.S.C. § 12133, and 29 U.S.C. § 794a; and

4. Order such other, further, or additional relief as the Court deems equitable, just, and proper.

DATED this 2nd day of July 2021.

Respectfully submitted,

/s/ Vanessa Zapata

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VERIFICATION

I have read the factual assertions in the foregoing complaint regarding my daughter, M.A.C., and pursuant to 28 U.S.C. § 1746, I declare under penalty or perjury that the foregoing is true and correct. Executed in Clarkesville, Tennessee on July 1, 2021.

/s/ M.E.C.

M.E.C.

VERIFICATION

I have read the factual assertions in the foregoing complaint regarding my daughter, Scarlet Burk, and pursuant to 28 U.S.C. § 1746, I declare under penalty or perjury that the foregoing is true and correct. Executed in Fayetteville, Tennessee on July 1, 2021.

/s/ Felicia Burk

Felicia Burk

VERIFICATION

I have read the factual assertions in the foregoing complaint regarding my daughter, Binta Barrow, and pursuant to 28 U.S.C. § 1746, I declare under penalty or perjury that the foregoing is true and correct. Executed in Knoxville, Tennessee on July 1, 2021.

/s/ Sadiatou Jallow

Sadiatou Jallow

VERIFICATION

I have read the factual assertions in the foregoing complaint regarding my brother, Jay Bryant, and pursuant to 28 U.S.C. § 1746, I declare under penalty or perjury that the foregoing is true and correct. Executed in Mohawk, Tennessee on July 1, 2021.

/s/ *Drama Bryant*

Drama Bryant

VERIFICATION

I have read the factual assertions in the foregoing complaint regarding my daughter, Amanda Casey, and pursuant to 28 U.S.C. § 1746, I declare under penalty or perjury that the foregoing is true and correct. Executed in Telford, Tennessee on July 1, 2021.

/s/ Ronda Coggins

Ronda Coggins